SPINAL CORD

Vol. 4 No. 1

October, 1992

Cheshire Gardens Becomes a Reality

For Mary Anita Andrews, living in the community again in an accessible environment with other people with disabilities, sharing resources, household duties and social interaction was a dream. Though Mary Anita did not see her dream fulfilled, Cheshire Gardens, a group living environment for people with disabilities, may provide a dream come true for other Arkansans.

Cheshire Gardens, 2001 Wilson (off Kanis Rd. behind the Baptist

KIDS SPORTS CLINIC

On Saturday, November 21, 1992, children ages 6 - 16 with disabilities are invited to a Sports Clinic sponsored by Fort Smith Rehabilitation Hospital's Child and Adolescent Rehabilitation Program Interdisciplinary Team. Registration will begin at 8:30 a.m., followed by Sport Activities (including Basketball, Volleyball, T-Ball, and other adaptive sports activities) from 9:00 a.m. to 12:00 noon. From 1:00 to 3:45 p.m. the "Shootin' Stars" Basketball Game will be the main attraction.

The Sports Clinic is free of charge and will be held at Raymond E. Wells School, 1211 Wells Drive, Greenwood, AR. (Greenwood is located approximately 18 miles south of Fort Smith on Hwy. 10). Permission slips must be signed by the parent/guardian of all participating children. Please call Terrina at 785-8551 by November 16 to pre-register your child. See all you good sports there!

Medical Center area) is a six bedroom, three bath, fully accessible home that has been approved for **HUD Section Eight low income** housing. A group living environment, each resident will have their own bedroom (that they furnish), share a bath (some with roll-in showers) with one other resident and share a common living room and kitchen. Though the home will not be staffed full time, a management aide will be available to assist residents with shopping and routine house maintenance. Twenty-four hour emergency call

coverage will also be provided by the Arkansas Enterprises for the Developmentally Disabled (though the home is not designed for the Developmentally Disabled population). Each resident is responsible for their own cooking, cleaning, laundry and personal care needs.

Cheshire Gardens is expected to open October 17th and applications are presently being accepted. To obtain an application and/or arrange a tour of the home, call AEDD at 666-0246.

Stacy Willis New Little Rock Case Manager

Stacy Willis accepted the Little Rock Case Manager's position and began her employment with ASSCC in July, 1992. Ms. Willis is a Certified Rehabilitation Counselor who was employed by UALR prior to assuming her duties with the Commission.

She obtained a B.A. in Psychology in 1987 and earned her Masters in Rehabilitation Services in 1989 from Florida State University in Tallahassee. Ms. Willis has participated on several committees advocating for individuals with disabilities. She currently serves as



President of the Arkansas Spinal Cord Injury Association, is a member of the ADA Roundtable and was recently appointed to the Governor's Commission on People with Disabilities.

ASSCC believes her experience in counseling, guidance, networking and knowledge of accessibility regulations will assist the agency in maintaining quality services for the South Pulaski County residents with spinal cord disabilities. After completing her three-week training session, Ms. Willis' top priority has become establishing contact, accessing needs and developing positive working relationships with the 159 individuals on her caseload.

SPINAL COURIER

Published quarterly by Arkansas State Spinal Cord Commission

Cheryl L. Vines Executive Director

Thomas L. Farley Editor

The Arkansas State Spinal Cord Commission does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

BUCKLE UP!

Super Spokes Finishes 1992 Season

Despite a rainy morning, our 1992 Super Spokes Saturday Program finished off with a bang at an awards ceremony and barbecue on September 19th. Super Spokes participants spent one Saturday a month since April working out and developing skills in activities such as obstacle course, basketball, tennis, roadracing and gymnastics. Working with their Rollin' Razorback coaches, all of the athletes worked hard and made great progress.

At the Awards Ceremony, each athlete received a participation medallion to remind them of their accomplishments. The highlight of the day was the surprise presentation by Quickie Designs Wheelchair Company representatives to the Most Outstanding Athlete for 1992. Jason Russell, 12 years old, of Little Rock was this year's recipient. Super Spokes '92 was sponsored by Horton's Orthotic Lab in cooperation with Sports Unlimited, the Rollin' Razorbacks, the Arkansas Spinal Cord Commission and Quickie Designs/ Sunrise Medical.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Dear Editor,

I thought the readers of the Spinal Courier might enjoy a word search puzzle. The enclosed puzzle is based on services that the ASSCC provides to its clients.

The object is to find all the words listed below in the word search square. Circle each word in the square and check it off the list as you find them. Remember that

words can run up, down, diagonal, forwards (left to right) and backwards (right to left). Good luck!

Dee Ledbetter ASSCC Grant Secretary

I hope you readers have an easier time than I did finding all these words. It took me 12 minutes to find them all. Drop me a line and tell me how you liked this puzzle. Thanks Dee. Editor.

Word Search Puzzle No. 1: ASSCC Services

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PEOPLE									GROUPS				
WITH									ADVOCACY				
DISABILITIES									INFORMATION				
PROMOTING									RECREATION				
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ADA Training to be Offered in Helena

Mid-Delta Community Services will offer one-hour training sessions on the Americans With Disabilities Act to local businesses and people with disabilities beginning September 25. The Americans With Disabilities Act is a comprehensive law that provides rights to people with disabilities in employment, state and local government, transportation, and telecommunications. The law was enacted July 26, 1990, when it was signed by President Bush.

The sessions will be conducted by Elaine Canady, Mid-Delta's ADA Coordinator, and will address employment and public accommodation. Ms. Canady received training provided by the Disability Rights and Education Defense

Fund and has been an advocate for people with disabilities for several years.

The training is free to local businesses and people with disabilities. Scheduled dates for training are: September 25 and 30; October 12, 14, 23, and 28; November 4, 6, 9 and 16; December 2, 4, 9 and 11. Training will be conducted from 2:00 - 3:00 p.m. at the Mid-Delta main office located at 610 South Biscoe Street, Helena, Arkansas. For additional information or to request training, interested individuals should contact Elaine Canady at 338-6406 from 12:30 - 4:30 p.m. or at 338-3803 after 5:00 p.m.

Delta Service Corp Begins

Delta Service Corp, a cooperative state effort of Arkansas, Louisianna and Mississippi, is developing a model national service program promoting citizen involvement. The program, coordinated in Arkansas by the Office on Volunteerism, will provide volunteer job opportunities for community service work in 42 Arkansas counties. Full time volunteers will receive a subsistence stipend (funds to assist with living expenses that will not be counted against SSI or SSDI income) and may also receive health care and vacation leave. The Corp is recruiting Arkansans with disabilities to be part of this exciting project. If you are interested in obtaining an application for the Delta Service Corp (training classes begin in November and in February) contact ASSCC at 324-9624 or the Office of Volunteerism at 682-7540.

Americans With Disabilities Act Compliance

As most of us are aware, the Americans With Disabilities Act (ADA), Public Law 101-336, was signed into law on July 26, 1990. Many people worked long and hard to make this civil rights legislation law, and since 1990 many individuals, advocates, businesses and government agencies are working to make it a reality.

The Spinal Cord Commission, a state agency, falls under Title II of the ADA. We are charged with making all of our facilities and programs accessible to people with disabilities. Since we were established to provide services to people with disabilities, this seemed an easy project. However, to truly make our programs accessible will be a long ongoing process and will continue to require input from our consumers as well as our staff.

The Arkansas State Spinal Cord

Commission does not discriminate on the basis of admission or access to or treatment or employment in its programs or activities. In order to monitor our compliance, Ms. Bettie Tapp, ASSCC Case Manager, 115 Market Street, Hot Springs, AR 71901, (501) 623-4479 voice and 623-9681 tdd, has been appointed our ASSCC ADA Coordinator. Any complaints or grievances related to ADA compliance of Spinal Cord Commission services should be addressed to Ms. Tapp.

The Spinal Cord Commission has developed an ADA Compliance Plan, including the federally mandated transition plan for facility accessibility. The Commission is working with the Department of Human Services on accessibility issues in many of our field offices, and plans are in place to meet the mandated July 1995 deadline for compliance. Copies of the Com-

pliance Plan are available for review in the Administrative Offices of ASSCC at 1501 No. University, Ste. 470, Little Rock, AR 72207. Individuals requiring information in alternate formats should contact the ADA Coordinator or Executive Director Cheryl Vines.

The members of the Spinal Cord Commission, along with our staff, are committed to both the letter and the spirit of the Americans With Disabilities Act and are doing all that we can to make our own agency meet compliance, as well as assisting our clients in advocating with businesses and other community agencies to meet access and equal opportunity needs. It's not an instant cure, but in the long run the ADA may have more sweeping effects than any civil rights legislation to date. For more information on the ADA. contact the ADA Roundtable at 221-1330.

RESULTS OF STUDY ON CHRONIC PAIN CONDUCTED AT SPINAL CORD INJURY CONFERENCE, JUNE, 1991

Last year, some of you experiencing chronic pain agreed to participate in a study at the annual Spinal Cord Injury Conference, Holiday Inn West. Participants were asked to respond to a questionnaire regarding type and frequency of pain. The same participants were again given the questionnaire after lunch to determine if feelings of pain had changed in any way.

You will recall that during lunch, a comedian entertained. Studies conducted worldwide have shown that laughter relieves pain. The purpose of our survey was to determine if laughter had any effect on chronic pain experienced by persons with spinal cord injuries and if so, to what degree.

The questionnaire was given before lunch and immediately after lunch to prevent any workshop or other information from affecting the results. There were nine male and three female participants. The average age was forty years and the average length of time since injury was eight years.

The following graph shows that for most types of pain, a decrease was indicated. There was a significant decrease in throbbing and stabbing pain. Only two types of pain (gnawing and fearful) did not show any decrease.

Norman Cousins, well known writer and lecturer, experienced severe pain after a serious injury. After an extensive study that involved many pain sufferers, he reported that fifteen minutes of "belly laughter" provides up to two hours of pain relief. Since the re-

sults of our survey agree with others that have been done throughout the United States and other countries, perhaps it would be well to tap into those things that provide laughter. Spend time reading humorous articles, watching funny movies or just talking to someone who makes you laugh. Maybe one of the best relievers of pain is available to all of us -- without prescription.

Our thanks to Dr. Randy Mowry who tabulated the statistics for this project.

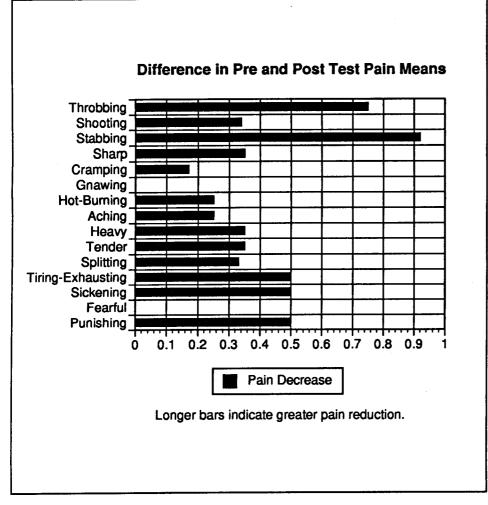
Chronic Pain Resource List

National Chronic Pain Outreach Association 7979 Old Georgetown Road #100 Bethesda, MD 20814-2429 (301) 652-4948

NCPOA is a nonprofit organization which operates an information clearing house about chronic pain and is management; publishes a quarterly newsletter. Lifeline; helps develop local support groups for people with chronic pain and their families; has a good recommended reading list; has access to directories and can give you information about pain clinics and medical professionals in your area.

National Health Information Center PO Box 1133 Washington, D.C. 20013-1133 (800) 336-4797 (301) 565-4167 in Maryland

This organization is a service of The Office of Disease Prevention and Health Promotion, a U.S. Public Health Service. They can refer information on specific diseases, heath education materials, nutrition, exercise, and many other general heath topics. They can give you addresses and phone numbers of organizations; and/or refer questions to appropriate organizations.



RUN THE HEIGHTS ON NOVEMBER 7

Calvary Baptist Church at 1901
North Pierce, Little Rock, will be
hosting a 5K Run on November 7.
There will be first, second and
third place awards for male and female winners in each of 13 divisions, including a wheelchair division. There will also be a Kiddie
K for preschoolers, led by Marty
Johnson, national Wheelchair racer. Each child in the Kiddie K
will receive a ribbon.

Registrations completed before November 1 will be \$10.00. From November 2-6, the fee is \$12. and on race day, the fee is \$15. A portion of the fee goes to the Rice Depot, the Heifer Project International and World Hunger of the Southern Baptist Convention. Corporate sponsors include, Baptist Rehabilitation Institute, Pepsi, Cool 95, Sportstop, Harvest Foods, Pulaski Bank, Clear Mountain Spring Water and Little Rock Life. Race time begins at 8:00 a.m. with the wheelchair division, followed at 8:02 a.m. by runners. The Kiddie K will begin at 9:00 a.m. Following the Awards Ceremony, there will be drawings for meals, business gifts and coupons.

Registration forms may be obtained at Sportstop or at Calvary Baptist Church. For more information, call Tommy Anthony at 663-8303. There will also be a Craft Fair in the Family Life Center near the finish line. The Craft Fair, including a Bake Sale, will be from 8:30 a.m. - 3:30 p.m.

How Do I Access Vocational Rehabilitation or Independent Living Services?

The Division of Rehabilitation Services has programs available to assist individuals with disabilities to become employable and/or to live independently in the community. The Division of Rehabilitation was mandated under the Rehabilitation Act and receives funding from the federal and state governments. You, as a person with a disability, have a right to apply for services and a right to be evaluated and determined eligible or ineligible for services.

Your rights are:

- 1. Confidentiality of information;
- 2. Prompt, fair and adequate service;
- 3. Non-discrimination in regard to sex, race, color, age, creed, national origin or disability;
- 4. Right to appeal any decision made.

Your responsibilities are:

1. Cooperate with your counselor,

- 2. Participate in your rehabilitation process;
- 3. Communicate your needs;
- Keep records of contacts with your counselor and papers he/ she gives you;
- 5. Remember and do what is expected of you -- keep appointments, call to cancel or reschedule:
- Disagree when necessary -- politely tell your counselor when you don't agree and try to work toward a solution;
- 7. Ask questions -- no question is too dumb;
- 8. Appeal -- if you disagree, you must initiate any appeal.

For further information regarding vocational rehabilitation or independent living services in Arkansas, call 324-9215 (v/tt) or 1-800-482-1174 (v/tt) and ask for Verline Davis, Client Assistance Program Advocate, or Ms. Dale Anne Turrentine, CAP Director. A handbook is available titled, Vocational Rehabilitation in Arkansas.

Ten Fact Sheets Now Available

Two new fact sheets are available from the ASSCC Resource and Education Center. Fact sheet No. 8 discusses fertility for male spinal cord injury individuals and fact sheet No. 9 is devoted to developing an effective bowel management program.

Fact sheets are one page information pamphlets about specific spinal cord disability problems. With the addition of these two, a total of ten fact sheets are now available form the ASSCC Resource and Education Center. Single copies of fact sheets are free and can be requested from the Center or from any Case Manager.

The following fact sheets are available:

Fact Sheet #1: Heterotopic Ossification in Spinal Cord Injury

Fact Sheet #2: Preventing Pressure Sores in Spinal Cord Injury

Fact Sheet #3: Heat Intolerance in Quadriplegics

Fact Sheet #4: Common Urological Problems: Leakage Around a Catheter

Fact Sheet #5: Common Urological Problems: Frequent Catheter Changes

Fact Sheet #6: Foley Catheter Care: Urethral or Suprapubic

Fact Sheet #7: Attendant Care Services

Fact Sheet #8: Female Sexuality and Spinal Cord Injury

Fact Sheet #9: Male Spinal Cord Injury

Fact Sheet #10: Bowel Management in Spinal Cord Injury

Preventing Urinary Infections

by Shirley McClure, M.D. ASSCC Medical Director

Although kidney failure is no longer the leading cause of death for persons with spinal cord injury, urinary complications still account for much of their illness and health care costs. With good management, these complications are frequently preventable. Research has clearly demonstrated that the most important requirements for preventing urinary infections are:

Low Pressure Filling and Low Pressure Emptying

Low pressure filling means that while urine is flowing from the kidneys to the bladder, the bladder must be relaxed (low pressure) so that no force is required for the urine to get into the bladder. For this reason persons with bladder spasms are often put on antispastic medications such as Ditropan.

Low pressure emptying means that while the bladder is emptying no force is needed to get the urine out.

There are three basic methods of bladder management -- intermittent catheterization, indwelling catheter (either suprapubic or urethral), and condom drainage (for bladders that empty automatically). Each of these methods has specific advantages and disadvantages and there is no method that is ideal for everyone. Each person must be carefully and frequently evaluated to determine what is best. Bladder function may change with time so that a method that worked well as first may no longer be appropriate.

When properly selected, any of these three methods can provide the necessary low pressure filling and emptying. How can one know when bladder management needs to be changed? The most frequent warning sign is acute urinary infection. This does not mean just a positive urine culture, but acute illness with a fever, usually over 102 degrees. Every episode of infection should be carefully analyzed to determine what might have caused it and what needs to be done to prevent further episodes. In most cases there is clear evidence of increased pressure within the 24-48 hours before the fever started.

Typical examples are:

Indwelling catheter -- the catheter became blocked and by the time it was changed, the bladder was overfilled (sometimes over 1000 cc).

Intermittent catheterization -- the bladder was allowed to get too full before the catheter was inserted for emptying. Ideally the bladder should not have more than about 400 cc when it is emptied. Overfilling is especially likely to occur in persons who cannot feel when their bladder is full.

Condom drainage -- the urinary sphincter (the muscle that prevents the bladder from emptying) fails to relax and the bladder has to exert considerable pressure to get urine out. Although the bladder may still be able to empty (with low residual urine), the most common sign suggestive of increased pressure is a history of Autonomic Dysreflexia*. Treatment of the infection must include good bladder drainage in addition to antibiotics. In most cases this means using a catheter until the bladder can be carefully evaluated. Although once considered very desirable, this method of management is now considered more risky and needs careful follow-up.



Anyone who has as many as two episodes of acute urinary infection in six months should have a complete diagnostic workup to determine why the infections occurred! Each episode of acute infection does permanent damage to the kidneys, so every effort should be made to prevent further episodes.

The most common preventable cause of infection is failure to follow a management plan correctly. This could be due to failure to understand instructions, but is more often due to poor compliance. However, other causes such as bladder or kidney stones must also be considered.

Anyone needing more information about bladder management may contact the Spinal Cord Commission.

* Autonomic Dysreflexia -- This is a potentially serious complication. Anyone not familiar with it should contact their Spinal Cord Commission Case Manager for further information.

Rollin' Razorbacks Game

The next game of the Rollin' Razorbacks will be held at Sylvan Hills High School, Hwy 107, North of Sherwood, on November 7th & 8th. This is the Arkansas Valley Conference Tournament and will feature many fine teams in addition to the Razorbacks. For more information about the Rollin' Razorbacks and their 1992 -1993 schedule call 501-834-8513. See you at the game!

PARALYMPICS '92 REPORT

WE ARE THE CHAMPIONS!

The USA Paralympic Wheelchair Basketball team posted an 8-0 record to win the gold medal at the Barcelona Paralympics on September 13th. The USA team beat competitors from Spain, Argentina, Canada, Japan, Great Britain, Australia and France in eight straight days of play to qualify for the gold medal game against Holland. In a great defensive contest before a packed house of nearly 14,000 at the Palau d'Sport in Badalona, the USA was victorious, 39-36. Tim Kazee was the leading scorer in the game and joined Arkansas teammates Darren Schenebeck, Gary Woodring, James Coughlin and in accepting the gold medal.

Arkansas swimmer Grover Evans did not fair as well. Caught up in

the "international politics" of a new functional classification system being tried for the first time in Barcelona, Evans a C6 quadriplegic, was pitted against amputees and individuals with other "non-paralysis" disabilities. Grover made the U.S. team proud, qualifying for the finals in all three of his events. Though he beat a U.S. record in one event, the competition was too tough and he posted two sixth's and a seventh.

Each of the Arkansas participants returned with great memories of this extraordinary experience, citing the opening ceremonies and lighting of the Olympic flame as one moment they will never forget. Look out Atlanta - we'll be there in '96!

A Service Dog Can Help!

Linda MacDougal, Coordinator for Santa Cruz County Commission on Disabilities in California, and her devoted service dog Chrysta made a disability awareness presentation to students of Redwood Elementary School in North Little Rock on September 4. Linda, an Arkansas native with quadriplegia as a result of polio, and Chrysta demonstrated how a dog can make a big difference in enabling individuals in wheelchairs to live as independently as possible.

On voice command, Chrysta assists Linda in performing everyday tasks. The students watched as Chrysta picked up objects, turned on light switches and opened and closed doors for her master. Linda told the students, "Chrysta brings me my clothes out of the dryer, goes to work with me and picks up mail at the office slot, and even gets her own dog food out of the cabinet. Once when I was home alone, I dropped a pin causing the pulley to come off my wheelchair. I was too far from the telephone, so Chrysta brought the phone to me so I could call for help."

Chrysta, part Labrador Retriever and part Rhodesian Ridgeback, was trained by Canine Companions, an organization in California that donates and places service dogs with persons who have disabilities.

Service dogs such as Chrysta have long been used to assist persons with vision impairments, but only recently have been found to be useful to persons paralyzed as a result of a spinal cord injury. Although service dogs for persons in wheelchairs are common in California, this is a new concept to Arkansas. Linda predicted, "these dogs will be well known to Arkansans within the next ten years."

For more information on service dogs, write Canine Companions for Independence at their Southeast Regional Center, PO Box 547511, Orlando, FL 32854-7511 or call (407) 834-2555 V/TDD.

A New Face at Spina Bifida Clinic



As many individuals who attend regular clinics are aware, there's a new Coordinator in the Spina Bifida Clinic and Program at Arkansas Children's

Hospital (ACH). Joyce Hunter, BSN, RNP, joined the clinic staff the first of September, replacing Teri Teer, RNP, CRRN, who moved over to the Urology Department at ACH.

Ms. Hunter, who originally hails from Scotland, has worked at ACH for 14 years, with 11 years in Pediatric ICU and 3 years on the Neurosciences Unit. In both of these posts she worked with kids with Spina Bifida (especially with shunt problems) and spinal cord injuries, and brings a wealth of experience to her new position. Presently she's busy meeting her 400+ clients and getting to know all of the providers and resource people who work with our kids. Be sure to introduce yourself next time you are at the clinic.

We miss Teri Teer and wish her well in her new position, and look forward to working with our new Coordinator, Joyce Hunter.



New Book Reviews

The ASSCC Resource and Education Center has recently added some new materials. Two new books are reviewed here:

The first book is titled Enabling Romance, A Guide to Love, Sex and Relationships for the Disabled by Ken Kroll and Erica Levy Klein.

Enabling Romance is the first illustrated guide to romantic and sexual relationships for individuals with disabilities, as well as the nondisabled friends, loved ones and professionals who influence their daily lives. Open, honest comments are provided by individuals and couples with a wide range of disabilities. Their insights and experiences have result-

ed in the development of an accurate and sensual book.

Written by a disabled husband and his nondisabled wife, Enabling Romance explores sexual variations and alternatives and contains specific chapters on spinal cord injuries, Multiple Sclerosis, amputations, neuromuscular disorders, as well as several other disabilities. Advice on family planning, safe sex and strategies for establishing intimacy are also included.

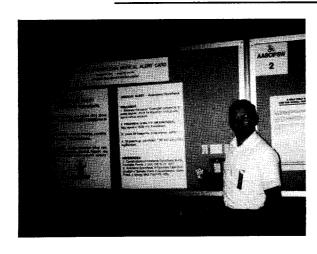
The second book by Sefra Kobrin Pitzele is titled We Are Not Alone, Learning to Live with Chronic Illness.

This book offers practical living strategies and guidance to individ-

uals with chronic illnesses such as Arthritis, Multiple Sclerosis, Diabetes and advice for those who care for them. Drawing on first-hand experience, the author is a "friendly guide" to coping with chronic illness, from overcoming the trauma of the diagnosis to managing daily routines "with humor, dignity, and hope."

We Are Not Alone also provides a detailed listing of special services and self-help organizations, a bibliography of useful books and articles, and an up-to-date survey of adaptive living devices. It is an excellent resource guide for any individual no matter what their disability.

These books and other materials are available for loan. Call Loretta Decker at 324-9628 to check one of these books out.



poster at the 1992 American Association of Spinal Cord Injured Psychologists and Social Workers Conference. The conference was held in Las Vegas, Nevada, September 7-11, 1992. Robert's presentation entitled, "Autonomic Dysreflexia Medical Alert Card" was based on the wallet size card developed by ASSCC Medical Director Shirley McCluer. The card provides critical medical information to physicians, hospitals, and other health care professionals and has created a much needed awareness. During the conference approximately 500 wallet size cards were distributed.

ASSCC Case Manager Robert Griffin was selected to present a

Printed on recycled paper.

SPINAL COURIER

Arkansas State Spinal Cord Commission 1501 North University, Suite 470 Little Rock, AR 72207

Commission Members:

Grover Evans - Jonesboro Sloan Lessley - Calico Rock Russell Patton - Jonesboro (Chair) Glennis Sharp - North Little Rock Sheila Galbraith Bronfman - Little Rock

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